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review

Understanding challenging behaviour in people with severe and profound intellectual disability: a stress-attachment model

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Abstract

Background Advances in our knowledge of attachment, stress and coping may foster new explanations for the development of challenging behaviour in people with intellectual disability (ID).
Method Research on stress and coping among people with ID was reviewed initially, and then studies on the security of the attachment relationships of people with ID with their caregivers were analysed.
Results There is evidence that people with ID are more vulnerable to stress and use less effective coping strategies. Furthermore, the body of studies on attachment indicates that people with ID are at risk for developing insecure, especially disorganized attachment. There is evidence from other populations that the combination of stress, and insecure or disorganized attachment may put people at risk for developing behaviour problems.
Conclusion A stress-attachment model of the development of challenging behaviour among people with ID shows promise as an explanatory framework. The uncovering of these developmental mechanisms may be particularly useful for the prevention of behavioural problems.

Keywords attachment relationships, challenging behaviour, psycho-physiological stress

Introduction

Although precise estimates of the prevalence of challenging behaviour in people with intellectual disability (ID) are still being debated (Deb & Bright 2001), most figures vary between 30% and 60%. The more serious the disability, the higher the prevalence of challenging behaviour. This prevalence is judged to be approximately three to five times as high as in normative populations (Došen 1990). We have only limited understanding of the origins of challenging behaviour, which can severely diminish the quality of life of the affected individuals and which often poses treatment dilemmas which are difficult to resolve. If challenging behaviour is to be prevented, theories as to its origins are indispensable. In this paper, the present authors develop an explanatory model of challenging behav-

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iour based on theories about stress and attachment. They focus on people with severe and profound ID. This specification is important because the level of cognition plays an important role in coping with stress, and in the development of attachment relationships and their later cognitive representations. The authors conclude by outlining some research questions which result from the integration of stress and attachment theories on challenging behaviour.

Psychological stress and coping

Psychological stress is defined as the subjective experience of challenged psychological well-being or challenged homeostasis (Lovallo 1997; Baxter *et al.* 2000; Lovallo & Thomas 2000). Stress is seen as a function of the gap between perceived societal demands and perceived competence to handle them. Lovallo (1997) proposed a two-stage appraisal system to explain the processing of psychological stress. In the first stage, people evaluate events for their threat value. They evaluate the extent to which their commitments and belief systems are endangered by the event in order to recognize dangers and to start evolving a plan to deal with them. If this first appraisal is 'non-threat', the event can be ignored. On the other hand, if this first appraisal is 'threat', it sets in motion the biological system, the sympathetic component of the autonomous nervous system: acceleration of heart rate, rise in blood pressure, respiration, muscle tone and endocrine output. The body's autonomic and endocrine control-systems are in place to deal with threats to homeostasis, and therefore, their purpose is to deal with psychological stress. The first threat appraisal also enforces a secondary appraisal of the availability and expected effectiveness of coping-resources and options to handle the stress.

Two outcomes are possible:

1 If resources are not available or are appraised as ineffective, helplessness is felt and the stress is perceived to be uncontrollable. As a result, the appraised threat and the accompanying psycho-physiological responses increase, causing what is known as hyper-arousal (Schore 2001b). In the long run, this can lead to a situation in which children can disengage from stimuli in the external world, which is known as hypo-arousal. This phenomenon of dissociation is found to be a parasympathetic regulatory strategy that occurs in situations of extreme helplessness to foster survival: an escape when there is no escape. The behaviour-inhibiting steroid cortisol is particularly associated with these extreme negative emotions, and endogenous opiates induce pain numbing and blunting (Lovallo 1997; Schore 2001b). This dissociation phenomenon may also be associated with the frequent self-injurious behaviour of people with ID in stressful situations (cf. Russ *et al.* 1992).

2 On the other hand, if this secondary appraisal of coping resources is positive, it may set in motion problem-focused coping behaviour (e.g. gaining information or changing the event) that can effectively reduce the threat value of the event. Alternatively, it may engender emotion-focused coping behaviour, which merely limits emotional disruption through (defensive) psychological re-formulations of the stress events or of the belief system, thus minimally changing the stress event itself. Each coping strategy has its costs and benefits. Problem-focused strategies may be costly in terms of energy, but they can potentially lessen the stress value of an event. Initially, emotion-focused strategies are less energy-consuming, but in the long term, they are more costly because of the continued drain on coping resources (Lovallo 1997).

Psychological stress and coping among people with intellectual disability

A number of studies (Bramston 1993; Chaney 1996; Bramston & Cummins 1998; Bramston *et al.* 1999; Bramston & Fogerty 2000) have shown that people with ID are at risk of psychological stress. Theoretical explanations of this risk point to their intellectual handicap, their problems in appraising and processing information, their need for a structured and predictable environment, and their limited behaviour repertoire (Gardner & Sovner 1994). In addition to developing low self-esteem and a general feeling of incompetence, people with ID are at risk of developing learned helplessness (cf. Olson & Schober 1993), a vision of their life as one of low controllability (Seligman 1979), in which the primary appraisal of threat and secondary appraisal of coping resources are by definition negative (for empirical psycho-

physiological evidence of this phenomenon, see Lovallo 1997). In this way, the coping skills of people with ID are affected, and as a result, they may perceive (secondary-appraised) stress in a more frequent, intense and sustained manner than the general population. This may be particularly true for people with severe and profound ID. Frequent and sustained stress may put the biological response systems of these individuals into an almost permanent state of activation, which results in the development of hard-wired maladaptive responses to even low levels of stress (Perry *et al.* 1995; Van der Kolk *et al.* 1996; Schore 2001a, b). Many events which appear not to be stressful for high-functioning individuals are stressful for people with ID (Bramston 1993; Chaney 1996). In particular, a great deal of stress is reported from negatively perceived interpersonal relationships with peers and others (Bender *et al.* 1999; Bramston & Fogerty 2000).

One of the problems in the study of the treatment and prevention of stress among people with severe and profound ID is that their subjective experience of stress is often hard to assess. Physiological studies may address this problem. Because psychologically stressful events can change a person's physical state a great deal (Lovallo 1997; Schore 2001a, b), it is useful to study the concomitant physical and physiological changes, especially in people with severe and profound ID who have problems in communicating their perceived stress. In studying psychological stress in this group, endocrine output, vital signs, temperature and bodily expressions can be monitored as an indication of their perceived stress.

Chaney (1996) evaluated the histories of stress and challenging behaviour of 35 institutionalized subjects with profound ID, and put them in different situations which were not considered threatening by others. In these situations, heart and respiration rate, body temperature and blood pressure were monitored. All but two of his subjects showed substantial signs of stress, and a strong association was found between these signs and their history of long-term stress, stress diseases and their history of challenging behaviour. These reactions were explained as being the result of helplessness, the insecurity of people whose disabilities prevent them from adjusting to perceived stress in changing situations.

Neumann *et al.* (2000) mentioned suggestive differences in baseline levels of total cortisol in groups of people with ID, depending on whether they engaged in self-injurious or stereotyped behaviour, indicating an association between the stress-hormone cortisol and serious challenging behaviour. Also using various physiological measurements, Thomas *et al.* (1985) showed that people with impairments in verbal skills were typically unable to take advantage of social support in coping with stress. The high proportion of often intervention-resistant challenging behaviour in people with ID may be understood as maladaptive responses to perceived stress. Several studies have indicated that cumulative psychosocial stress is positively associated with challenging behaviour and that adaptive competence in coping is negatively associated with challenging behaviour (Eaton & Menolascino 1982; Stack *et al.* 1987; Verhoeven & Tuinier 1996; Bender *et al.* 1999). Psychophysiological intervention research may prove the association between psycho-physiological stress management and challenging behaviour to be causal because medication directed at the de-arousal phenomenon (mediated by the cortisol-dependent stress homeostatic mechanisms) has resulted in reduced challenging behaviour (Verhoeven & Tuinier 1996; Lovallo 1997; Lovallo & Thomas 2000).

Attachment and its relation to stress management

In young children, seeking physical security or comfort can be understood as a way of coping with stressful situations. The attachment system acts as a kind of homeostatic mechanism for modulating anxiety and stress by seeking out an attachment figure for security and protection (Bowlby 1978; Kobak 1999; Schore 2001a, b). The attachment system appears to fulfil this function even in the face of insensitive care-giving, albeit in a less straightforward fashion. In insecure attachment relationships, these normal coping strategies break down and establishing felt security is complicated.

Main (1990) proposed a useful conceptualization of the secondary strategies which insecurely

attached children use to maintain homeostasis: they ensure that their attachment figure remains available by minimizing (avoidance) or maximizing (resistance) the expression of attachment signals. Both strategies entail distortion or exaggeration of perception and affect. In a sizeable minority of attachment relationships (approximately 15% in normative samples; Van IJzendoorn *et al.* 1999), children are observed to display disorganized attachment behaviour under stress (according to the definition of Main & Solomon 1986). In these relationships, the behavioural strategy to deal with stress in the presence of the attachment figure appears to break down or to be absent. In addition to effects on stress regulation in the immediate situation, a secure attachment system in children may also act as a moderator of initial temperamental disposition, making children more resilient in the longer term (for a review, see Fox & Card 1999).

A meta-analysis on animal models and human experiments indicated that attachment contributes to individual differences in susceptibility to stress (Maunder & Hunter 2001). In contrast, when attachment figures are themselves sources of fear, the attachment system is incapable of fulfilling its function: the source of security is at the same time the source of fear (Main & Hesse 1990). Frightening parental behaviour (Schuengel *et al.* 1999) or abuse (for a meta-analytic review, see Van IJzendoorn *et al.* 1999) is found to predict disorganized attachment.

According to some theorists (Bradley 2000; Schore 2001b), disorganized attachment may interfere with the early development of the right brain's stress coping system. Lovallo (1997) also described how the neurophysiological mechanisms triggered by early maternal attention and nurturing would be responsible for dampening of stress levels of cortisol later in life. Indeed, some studies have found that cortisol levels take longer to drop after attachment-related stress among children disorganized in their attachment relationship (Spangler & Grossmann 1993; Hertsgaard *et al.* 1995). Consistently, children with disorganized attachment appear less able to regulate their behaviour, as shown by the predictive association between disorganized attachment in infancy and externalizing behaviour problems at pre-school or school age (for a meta-analytic review, see Van IJzendoorn *et al.* 1999).

Attachment among people with intellectual disability

Several studies have presented distributions of secure and insecure attachment patterns among children with ID. However, an important caveat is the validity of the attachment instruments used because these have been developed for normative samples. This issue has not yet been resolved. For example, children with Down's syndrome (DS) appeared to be less impressed by the Strange Situation procedure in some studies (Thompson *et al.* 1985; Van IJzendoorn 1994; Vaughn *et al.* 1994). However, a study by Berry *et al.* (1980) showed that children with DS did become distressed in the Strange Situation.

Ganiban *et al.* (2000) assessed the emotional reactions of children with DS to the series of separations and reunions in the Strange Situation using a detailed coding system of distress vocalizations, showing that differences in emotional reactivity did not explain the distribution of attachment classifications. Therefore, the overt lack of stress display may not necessarily mean that the Strange Situation is invalid as a measure of attachment for children with DS. Summarizing the available studies, Van IJzendoorn *et al.* (1992) showed that children with a developmental delay and with autism were significantly more likely than children from normative samples to be classified as insecure (especially avoidant).

Early studies of attachment quality, as summarized by Van IJzendoorn *et al.* (1992), employed the original classification system of three attachment groups: secure, avoidant and resistant. In view of the possible links between impaired stress regulation and disorganized attachment, the present authors discuss studies which included the fourth, disorganized category, in more detail. These studies were summarized by Van IJzendoorn *et al.* (1999). For the total group of people with 'neurological abnormalities', including autism, DS, cerebral palsy, cranial and other neurological abnormalities, the above authors found significantly fewer people to have secure attachment and more people to have a disorganized type of attachment.

Vaughn *et al.* (1994) were among the first to find an overrepresentation of disorganized attachment among children with DS. However, the above

authors warned that this overrepresentation could be a result of developmental delays as well as the consequence of relational risk factors. Methodological concerns have also been expressed because the coding system for the disorganized category might not be suitable for people with neurological problems. However, Pipp-Siegel *et al.* (1999) argued that it is possible to use the coding system with minor adaptations. For example, Willemsen-Swinkels *et al.* (2000) excluded autistic symptoms from the disorganized attachment classification system, and compared 19 typical children, 19 children with language disorders, 19 children with pervasive developmental disorder (PDD) without ID, and 13 children with PDD and comorbid ID. Mere PDD was not associated with insecure or disorganized attachment. However, the combination of PDD and ID was significantly associated with elevated rates of disorganized attachment.

Other studies (e.g. Ganiban *et al.* 2000) also found (slightly) elevated rates of disorganized attachment, even though they excluded disorganized attachment behaviours such as dazing or rocking when these behaviours were not only displayed in the presence of the attachment figure, but also in the presence of the stranger. Atkinson *et al.* (1999) found that a minority (40–47%) of children with DS exhibited secure behaviour, but that a similar proportion was unclassifiable. The mothers of the secure behaviour group were found to be more sensitive. This is also an indication for the validity of the Strange Situation as a measurement tool for attachment among children with DS.

Precursors of insecure attachment

According to the evidence reviewed above, there is increased risk of insecure attachment, especially disorganized attachment, among children with ID. The present authors now briefly discuss the precursors associated with ID which may be responsible for insecure attachment: parental stress, ineffective parenting, children's limited cognitive skills and institutionalization.

Parental stress

Parents see the diagnosis of ID as their most stress-inducing life event (Baxter *et al.* 1995; Stolk & Kars 2000). Complicated resolution of the diagnosis may result in a chronic depletion of the psychic resources to deal with the daily demands of caring for a child with a disability (Janssen 1982; Marvin & Pianta 1996; Pianta *et al.* 1996; Emanuel 1997). One key to understanding these problems may be that some parents fail to integrate the internal working model of 'the happy child/family' prior to the diagnosis with an internal working model based on the real situation (Pianta *et al.* 1996). Pianta *et al.* (1996) found that non-resolution of a diagnosis of cerebral palsy corresponded to insecurity of the attachment relationship. In a pilot study among parents of children with ID, the present authors found a significant association between non-resolution by mothers (using the Reaction to Diagnosis Interview; Marvin & Pianta 1996) and teacher-reported challenging child behaviour (Mentink *et al.* in press).

Ineffective parenting

Parenting of children with ID is also a difficult job in itself, because of the atypical characteristics of these children (Baxter *et al.* 1995; Baxter *et al.* 2000). Children with DS are generally described as less reactive and less clear in their signalling behaviour, which makes it more difficult for parents to be sensitive and to find interaction with the child appealing and rewarding. Although these difficulties could be overcome by parents in principle (Van IJzendoorn *et al.* 1992), preventing insecure attachment may require special skills (Atkinson *et al.* 1999; Ganiban *et al.* 2000). Furthermore, children with disabilities appear more likely to be maltreated than non-disabled peers (Sullivan & Knutson 2000). A meta-analysis showed that maltreatment is a strong predictor of disorganized attachment among non-disabled children (Van IJzendoorn *et al.* 1999).

Children's limited cognitive skills

Although only very basic cognitive skills are required in order to use a specific person as a secure base (e.g. the ability to differentiate means from ends and object permanence; Cassidy 1999), some children with severe and profound ID may have difficulty developing these skills and using them effectively, especially under stress. For

example, children with deficient object permanence will be in an almost permanent state of separation distress. Children who have difficulty identifying and choosing means (attachment signals) to an end (contact or proximity) might also experience fewer secure base interactions. Atkinson *et al.* (1999) found that lower-functioning children were less frequently classified as secure in the Strange Situation. In the pre-school period, children with ID might lack the cognitive flexibility and planning skills necessary for developing a goal-directed partnership, in which parent and child coordinate each other's wishes and needs.

Institutionalization

The transition of children with ID into residential or community care is to be regarded as an extremely stressful event (Bramston & Cummins 1998), and as a major disruption of the caregiver–child relationship. These disruptions affect the attachment system (Cassidy 1999). Lack of continuity and reduced potential for sensitivity within professional caretaking pose additional risks even in children without ID (Howes 1999; Roy *et al.* 2000).

Discussion

Because of the many points of correspondence and common biopsychological foundations of theories of stress and theories of attachment, it is no surprise that the intersection between these two areas of interest provides fertile ground for multilevel research on coping at the intra-individual level and attachment at the inter-individual level (Diamond 2001). A next step would be to study the intertwining of attachment and stress across development in people with ID. First, the present authors reviewed evidence showing that people with ID have less adequate coping resources and that their attachment relationships are more often insecure (often disorganized). Without effective buffers against the impact of stress, people with ID might suffer the gravest physiological impact from stress. Secondly, there is a dearth of knowledge on the developmental processes leading up to psychopathology among people with ID, as indicated by aggression, self-injury, severe withdrawal, anxiety and depression.

Although it is sometimes recognized that, apart from constitutional factors, stressful life events might precede the onset of such problems, it is often unclear which processes are driven by these life events, and how these processes might be prevented, halted or reversed. The current review has argued for attention to a combination of factors involving coping skills, attachment relationships and developmental history. In a next step, a stress-attachment model of challenging behaviour might be used to underpin prevention and treatment of this behaviour. A crucial component in stress-attachment research in people with severe and profound ID is the possibility of measuring stress reactivity without having to rely on verbal reports. In this respect, technical advances, such as the ambulatory monitoring device (VU-AMS) for physiological stress-measurement, developed by De Geus & Van Doornen (1996), are promising (For details and references: www.psy.vu.nl/vu-ams).

Studies employing these and other methods to index the response of the organism have already proven their value in research on stress, attachment and behaviour problems among people without ID. First, measurements of the reactivity of the autonomic nervous system can shed additional light on the validity of the procedures to measure security of attachment among people with ID. Secondly, ambulatory measurement of stress reactivity enables study of the hypothesized relationship between hyper- and hypo-arousal and challenging behaviour in real-life conditions. Thirdly, physiological measurements of stress can be used to test whether interventions really have the desired effect of improving buffers against stress.

The present authors identified precursors for insecure attachment which are suitable for prevention or even intervention. However, efforts to help parents resolve the diagnosis of their child, to prevent child abuse, to stimulate sensitivity among caregivers and to avoid institutionalization impact on multiple domains. It is crucial to test whether these efforts result in dampening stress reactions. Another challenge is to find interventions with long-term effects on susceptibility to stress.

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